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Patient-Reported Outcomes: Successfully Scaling Up from Department to Institution

Chris Weiss is the Co-founder, President & Chief Executive Officer of Dynamic Clinical Systems. The DCS secure Web-based solution, Integrated Survey System® (ISS), enables patients to provide health history and outcomes data electronically, lowering the cost of data management, improving the value of data collected, enhancing control in decision making, and documenting empirical measurement of outcomes tailored to care. DCS's vision is to enable outcomes-based care over a patient's journey through the healthcare system.

Arguably, nowhere has Internet-based empowerment altered individual behavior more than around health decisions. Health information is no longer scarce – facts and opinions are abundant online. People are hungry for the information they need to make health decisions and maximize their quality of life. Based on Dr. James Weinstein's testimony at a recent Office of National Coordinator (ONC) hearing for "meaningful use" criteria, Dartmouth-Hitchcock Medical Center is doing just that. Weinstein, a spine surgeon and President of Dartmouth-Hitchcock Clinic, described in his testimony how patients can be fully engaged in their own care through the use of Dartmouth-Hitchcock's innovative health information technology. Weinstein held up a report during this testimony and said that the patient-entered data summarized on that report was more important to him than an MRI.

The system used to generate that report is called H-Quest, which is based on Integrated Survey System® (ISS) from Dynamic Clinical Systems, a Web-based solution for collecting, reporting, and analyzing patient-reported data to improve care and research. The moniker "H-Quest" is a tribute to both "health questionnaire" and the patient's ongoing "quest for better health." Weinstein's accompanying written testimony describes Dartmouth-Hitchcock's pioneering initiatives in Web-based patient-reported data collection, first implemented in its Spine Center to improve routine care, outcomes, and research. Early accomplishments in the Spine Center implementation included 98 percent patient survey compliance, 95 percent physician survey compliance, 60 percent increase in triage to Behavioral Medicine.

Based on this work and other similar patient-reported data collection initiatives at Dartmouth-Hitchcock, such as in its Comprehensive Breast Center and Hand Surgery clinic, leadership at Dartmouth-Hitchcock decided it was time to implement H-Quest in a standardized manner across the institution. The process began with the formation of a Steering Committee tasked with managing the implementation of H-Quest throughout the institution. The Committee led by co-chairs Carolyn Kerrigan, MD, MSc, and Mary Evanofski, OTR, brought together senior clinicians and administrators at Dartmouth-Hitchcock to define common goals and standards, evaluate implementation requests from clinical specialties, design common workflow and policies, and prioritize suggestions for enhancing the system.

Standardizing the Process

The Steering Committee designed a core, cross-specialty health survey and allowed for additional questions to be customized by each specialty. The health surveys were designed to not only collect traditional health information such as demographics, social history, and medical history, but also screened for broader health-related topics such as quality of life, mental well-being, substance abuse, domestic violence, advance directives.

Dartmouth-Hitchcock leaders recognized that in order to become a part of routine practice, H-Quest would need to be fully integrated into existing hospital systems, including its scheduling system, electronic medical record (EMR) system, data warehouse, and patient portal.

Using Patient Data to Improve Care

When a patient makes an appointment, the interface with the hospital scheduling system downloads relevant appointment information into H-Quest. Groups of surveys – a tailored set of individual surveys – are automatically "queued" or scheduled based on rules-based appointment parameters (department, specialty, clinician, appointment type), patient information (e.g., gender, age, past and current survey responses), and pre-defined timing parameters. The status of the survey (e.g., due date, completion, etc.) is displayed in role-based work lists and operational reports for tracking purposes. The patient is notified by email

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with instructions for opening and completing the survey. She also receives a phone number to call for assistance if she has password problems or other technical issues that interfere with completing the survey. If patients do not have access to a computer or e-mail or if they need assistance in completion of the survey on-line, they come in for a special appointment to complete the questionnaire via tablet computer in the waiting room or at a staff-assisted health education center.

Once logged in, the patient questions are administered based on survey group parameters (indicating question types, timing, branching logic, filtering logic, etc.). If the patient has previously answered specific questions, the questions may be skipped and linked in based on the defined timing parameters. For those questions that are repeated, the patient may see previous responses and update them (e.g., for questions related to past medical history) or may need to answer again without her previous answers (e.g., for questions related to symptoms or QOL). The survey presents the patient with an online consent form approved by the Institutional Review Board (IRB) to allow their health data to be used anonymously or non-anonymously for research purposes.

At the completion of the survey, the patient may be presented with a report based on her responses; with education and links to additional educational websites for topics such as treatment decision information, cancer resources, smoking cessation, alcohol issues, depression, advance directives, nutrition, fitness, financial aid, and domestic violence.

After the patient survey is submitted online, referrals may be automatically triggered to a specialist, such as a social worker or genetic counselor, based on patient responses and pre-defined rules in H-Quest. The referral is sent as an email to the specialty department or individual specialist with a link allowing the specialist to log into ISS to process the referral. Upon opening the referral from the work list, the specialist can see the rules that triggered the referral, view the Clinician Summary Report, and add information about that referral (e.g., contact attempts, resolution status).

Each submitted survey also generates a Clinician Summary Report which has been designed to provide an overview of patient responses in logical order for clinicians to use during patient consultations. The report includes a "red flag" section in which areas requiring more immediate attention and intervention are noted, such as moderate or severe pain, domestic violence, alcohol abuse, severe or frequent symptoms, or symptoms that have worsened significantly since the last survey. The reports also contain longitudinal graphs for follow-up patients (or patients who have completed parts of the survey in other specialties, such as primary care) and a summary of automated referrals that have been made.

Based on the pre-defined rules, H-Quest may also schedule a series of follow-up surveys to the patient, such as regular post-treatment surveys to track outcomes and monitor symptoms and symptom management at home. These surveys are prompted by a reminder email sent to the patient at the appropriate interval, asking the patient to log into the system and complete the Web-based survey from home. The patient's answers might trigger an intervention by the clinician if certain symptoms are getting worse. This follow-up data is also used for comparative effectiveness research to understand which treatments are and are not working well.

Data Analysis

Beyond its use for individual care, data entered by patients into H-Quest is stripped of identifying information and used for various purposes. Operational reports are posted on the facility's secure Intranet for common use to help administrators understand how well the patient data collection process is working for various clinical areas. Other reports provide clinicians with a view of aggregate survey responses, aggregate longitudinal outcomes over time, and health scores. Individual questionnaire responses can be converted to tab-delimited, HL7, or SAS format to be analyzed in more detail.

Public reporting of patient outcomes and quality of care information has been an integral part of the Dartmouth-Hitchcock approach. The institution's performance indicators (quality, safety, satisfaction, and responsiveness) are published on its public website, including patient-reported outcomes for some specialties.

Blazing the Trail

Leading the way down an unproven path always results in the discovery of a certain number of roadblocks, and the system-wide implementation of H-Quest was no different. Beyond the expected learning curve of any new change initiative, there were several aspects of the implementation which stand out as teaching points for other institutions.

"Our patients won't like this." Point to facts based on similar initiatives in other institutions that show that not only are patients willing and able to use automated tools to communicate their health information, but are very satisfied with the process. Weinstein's written testimony indicated that only a small percentage of Dartmouth-Hitchcock patients would prefer to communicate their health information by paper rather than computer.

"We're too busy." Emphasize the elimination of duplicate tasks from miscommunication. Spend as much time as necessary to develop a simple, user-friendly system that encourages people to see the surveys as less of a hassle. Clarify roles and procedures, and give everyone a vision of how the system will make their workload easier in the long run.

"We don't like change." Keep clinicians and staff informed of implementation goals and activities well ahead of time, and make sure to collect input and feedback often. Often, what they're really saying is that they don't like change which is forced on them without their input. Give them the training and support they need to feel comfortable with the new system and process.

"This isn't helping us." Be ready to measure and demonstrate the benefit of using this system and process, including improvements to individual care, patient populations, outcomes tracking, public reporting, and research.

"Fine, but what do we do now?" Take methodical care to build a foundation for success in the planning stages. Establish governance and roles to set strategy, policies, goals, and measures. Develop a core set of tools, data requirements, workflow, roles, and incentives. Select one department and implement a focused pilot. Update the system, data requirements, and processes based on the pilot results and begin implementing in other departments.

Dartmouth-Hitchcock's use of information technology to engage patients and measure outcomes is setting an example for care-givers and institutions across the country. Dartmouth-Hitchcock continues to calibrate its use of technology and is collaborating with others to understand what they have found to develop a comprehensive learning healthcare system capable of advancing science, improving care and outcomes, while controlling costs.